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ABSTRACT

The second in a series of three reports, this document presents findings of clients of Washington's Division of Developmental Disabilities (DDD), ages 22-29, who were living with their families at age 18 but now live elsewhere (group B). Findings are based on telephone interviews with families of 224 DDD clients and analysis of DDD records. The following topics are addressed: (1) characteristics and activities of clients and their families during the year before the clients moved from home; (2) differences between group B Ss and group A Ss (who remained at home); (3) ways in which families made the decision for the move; and (4) parents' perceptions of the clients' current circumstances and future plans. A description of methodology and a set of data tables are appended. (CL)

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Report:

DEVELOPMENTALLY DISABLED PERSONS IN FAMILY SETTINGS:

REPORT NO. 2

DIVISION OF ADMINISTRATION AND PERSONNEL

EC182033

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05-18B

DEVELOPMENTALLY DISABLED PERSONS IN FAMILY SETTINGS: REPORT NO. 2

Division of Developmental Disabilities Clients No Longer Living with Their Families

Wendy M. Cox
Wendell L. Wilson

March 1985

Program Research and Evaluation Section
Office of Research and Data Analysis
Department of Social and Health Services
Olympia, WA 98504

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STATE OF WASHINGTON
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Lee Bomberger, Chief

PROGRAM RESEARCH AND EVALUATION SECTION
Thomas Sykes, Supervisor

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EXECUTIVE SUMMARY

In 1983 the Division of Developmental Disabilities (DDD), within the Washington State Department of Social and Health Services, initiated a study of developmentally disabled persons who have lived with their families. This is the second in a series of three reports concerning that study. The first report focused upon DDD clients who were still living with their families (Group A). This report focuses upon DDD clients, ages 22 through 29, who were living with their families at age 18 and now live elsewhere (Group B).

Findings are based upon telephone interviews with the families of 224 DDD clients, as well as background information from DDD records. The following topics are included: (a) characteristics and activities of clients and their families during the year before the clients moved away from home, (b) differences between Group B clients (before they moved away) and Group A clients who remained at home, (c) how families made the decision for the client to move, and (d) how parents perceive the clients' current circumstances and future plans. Most questions about Group B clients pertained to their last year at home; this required parents to recall circumstances and events that occurred an average of five years prior to the interview. This historical perspective should be kept in mind in reviewing these findings, particularly comparisons made between Groups A and B. Major findings are summarized below.

Prior to the move away from home, how did Group B clients and their families differ from those who continued living at home (Group A)?

Based upon retrospective accounts of the year before Group B clients moved from home, this group appeared to differ from clients who remained at home in several respects:

- The parents of clients who moved away were slightly younger and more likely to be employed full time.

- Fewer Group B clients were classified as moderately to profoundly retarded (32% vs 42%), and fewer had chronic health problems (21% vs 30%).

- Prior to the move, clients in Group B had significantly lower social and communication skills and more non-dangerous behavior problems than Group A clients.

- Prior to moving away from home, more Group B clients were attending work, school, and training programs; 85% of Group B versus 69% of Group A participated in at least one of these scheduled activities.

What circumstances surrounded the decision for clients to move out of the family home?

- Two-thirds of the parents reported that their son or daughter was a DDD client prior to the move and that the family began planning for the move at least six months before it occurred.

- When asked what factors contributed to the decision, families most often cited seeking a change in social opportunities for the client (80%), the client reaching adulthood (71%), and availability of an appropriate residential setting (60%).

- Forty-two percent said that poor health of other family members was a consideration in the decision for their developmentally disabled relative to leave home.

- The reasons for clients moving away were not associated with any of the following client/family characteristics: clients' age, physical health status, or ability to perform daily living tasks; parents' age or marital status.

Where did these clients move?

- Most clients initially moved to regular group homes (53%) or independent living situations with or without support staff (21%).

- Eighteen percent moved to non-DDD residential settings (e.g., nursing homes, adult family homes, congregate care facilities) and less than 10% moved to institutions for the mentally retarded.

- Most clients have stayed in the same type of residential setting (66%) or have moved to more independent settings (26%) since the initial move from the family home.

What is the current and future status of these clients?

- Most parents expressed satisfaction with each aspect of the clients' current circumstances: living arrangement (88%); physical and mental health (84%); work, school or training program (81%); and social life (80%).

- Sixty percent of the families had made financial arrangements to provide for the client's future and 60% had made arrangements for a guardian or sponsor when they are no longer able to care for the client.

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CHAPTER I. STUDY OVERVIEW

Background

As of November 1983, over 40 percent of the nearly 12,000 developmentally disabled persons in Washington State who were Field Services clients of the Division of Developmental Disabilities (DDD) lived with relatives. This group included more persons than those in all DDD-sponsored institutional and community residential settings combined. Public policy in Washington State has generally encouraged families to support relatives, adults as well as children, who cannot live independently. In order to plan effective support services to families with developmentally disabled members, information was needed on the status of families who cared for developmentally disabled relatives. The present study was initiated in 1983 to provide such information.

The study addressed developmentally disabled persons in Washington State, ages 16 and above, who lived with their families or were living with their families at age 18. Study groups included current clients of the Division of Developmental Disabilities, as well as persons who appeared eligible but were not DDD clients. Descriptive information about this population was compiled to answer the following key research questions:

1. What are the characteristics of developmentally disabled persons who live with their families? What are the characteristics of their families?

2. What factors contribute to the family's decision to keep a developmentally disabled member in the home or seek another residential alternative?

3. For those who moved from the family home after age 18, where do they live and what factors were associated with their leaving?

4. How do eligible developmentally disabled persons who are not clients resemble DDD clients, and how do they differ?

Approach

To address these questions in a thorough yet timely manner, three distinct groups were studied in succession (Table 1.1). For each group the closest relatives or guardians of selected developmentally disabled persons were contacted and asked to participate in a structured telephone interview. For DDD clients studied, information was also solicited from Field Services records and from each client's Developmental Disabilities Specialist, i.e., case manager. Characteristics unique to each study group necessitated some differences in procedures for identifying study group members and in methods of data collection.

TABLE 1.1

DESCRIPTION OF STUDY GROUPS

	Population	Primary Focus
Group A	DDD clients now living with their families.	Describe the characteristics, activities, and status of the overall group; determine any age-group differences.
Group B	DDD clients living with their families at age 18, now living elsewhere.	Describe the characteristics and status of these clients prior to their leaving home; compare with Group A to identify factors related to out-of-home placements.
Group C	Non-DDD clients who appear DDD-eligible regardless of where they live.	Describe this "latent population" for DDD services and contrast with Groups A and B.

The remainder of this report describes the research design and findings which pertain to Group B. Detailed information about Group A and Group C are presented in separate reports.

Group B Overview

This phase of the research involved studying DDD clients in Washington State who were living with their families at age 18 and have since moved elsewhere. (Throughout this report the terms "parents" and "family" are used to include legal guardians or close relatives, as well as parents.) Only one age group was studied--young adults, who were 22 to 29 years old when the study was undertaken. This age group was considered a priority because the post-school years are a critical time when future living arrangements and weekly routines are often determined. However, this age cohort excluded school age children and adults over thirty years old, whose reasons for leaving home may have been quite different from the group studied.

There were two purposes for studying this group of clients. The first was to learn about the circumstances surrounding each family's decision for the developmentally disabled adult to live elsewhere: What were the factors associated with their leaving the family? Where did the clients move? The second purpose was to determine whether or not the clients who moved away from home were different from those who were still living with their families.

In order to achieve these purposes it was first necessary to identify DDD clients throughout the state who (a) were no longer living at home, and (b) moved away from home after age 18. Parents of non-institutionalized DDD clients (i.e., Field Services clients) who lived away from their families were contacted to identify individuals who met these criteria. Concurrently, personnel from the Residential Habilitation Centers (state institutions for the mentally retarded or RHCs) reviewed client records to identify residents who met these criteria. Families of the 288 clients thus identified--272 from Field Services and 16 residents of RHCs--were then asked to participate in a telephone interview. Further information about these clients was obtained from DDD case records. (See Appendix A for additional information about study methods.)

Of particular relevance for this group were data about clients just prior to the move: demographic characteristics, functional abilities, health, daily living experiences, and use of support services. Further attention was given to the family living situation at that time and how the family made the decision for the client to move elsewhere. Limited information was collected about the clients' current status and future plans or arrangements.

Most of the data collected about Group B clients were retrospective (based upon parents' recollections of the client's last year at home) while data concerning Group A clients were more current (based upon parent reports of the circumstances during the year preceding the interview). To minimize possible age-related differences, comparisons between Groups A and B used data from a corresponding age cohort within Group A: 264 clients with an age range (18-26) and average age (21) comparable to those for Group B clients during their last year at home. When comparisons are made between these two study groups, the different time frames should be noted.

Results are presented in subsequent chapters. Chapter II presents data about Group B clients and their families during the year before the client moved away from home and contrasts them with their peers who are still living at home (Group A). Chapter III describes when and how families made the decision for the client to move elsewhere, and Chapter IV discusses the clients' current status and future plans.

CHAPTER II. CHARACTERISTICS AND ACTIVITIES OF GROUP B IN COMPARISON WITH GROUP A

This chapter addresses two major purposes of this phase of the study: (1) to describe Group B clients and their families during the client's last year at home, and (2) to compare these findings with data about clients who remained at home (Group A) and note any differences between the two study groups. The descriptive information presented includes demographic data, client health and functional performance, home and community activities, daily living experiences, and support services received by the family. The findings presented in this chapter are based upon parents' recollections of their family circumstances during the year before the client moved away from home--a time period which ranged from 1 month to 11 years prior to data collection. Information about clients still living at home (Group A) focused upon families' circumstances during the year prior to data collection. To control for possible age differences between the two study groups, only data regarding Group A clients of similar ages were used in the comparisons with Group B. In this chapter reported differences between groups refer to differences considered statistically significant at the 95 percent confidence level.

Demographic Data

Table 2.1 summarizes demographic data for Group B clients and their families prior to the move and contrasts these data with Group A. Client demographics for Group B did not differ signficantly from Group A. About half the clients in Group B were male and three-fourths lived in urban areas. Most clients either attended special education classes in a regular school (56%) or attended a special, segregated facility for handicapped students (27%). Over three-fourths of the Group B clients had never lived away from home prior to age 18.

Comparison of family characteristics for each group revealed that parents of clients who remained at home were slightly older and less likely to be employed full time (Table 2.1). There were no significant differences between groups in family size, family income, number of parents in the household, or parents' health. While Group B clients were still living at home, the average family size was 4.5 persons per household, and 88 percent were two-parent households. In about 90 percent of the families at least one parent was characterized as in good health.

TABLE 2.1

CLIENT AND FAMILY DEMOGRAPHICS
BY STUDY GROUP

Client Demographics	Group B %	Group B n	Group A %	Group A n
Sex:				
Female	49	(109)	42	(111)
Male	51	(113)	58	(151)
Locale:				
Urban a/	73	(162)	79	(209)
Non-urban	27	(60)	21	(55)
Residential history:				
Always lived at home	78	(174)	85	(224)
Once lived in a state institution	9	(20)	5	(12)
Once lived elsewhere (other than a state institution)	13	(29)	10	(28)
Current or most recent school program:				
Special school/facility (segregated)	27	(31)	28	(74)
Special classes (regular school)	56	(65)	61	(159)
Some/all regular classes	9	(10)	8	(21)
Other	8	(9)	3	(6)
Family Demographics				
Annual income:				
Less than $10,000	18	(32)	25	(56)
$10,000 - 20,000	36	(65)	28	(65)
$20,000 - 40,000	39	(72)	38	(87)
Over $40,000	8	(14)	9	(20)
Parent employment:*				
At least 1 parent works full-time	79	(177)	63	(165)
No parent works full-time	21	(46)	37	(97)
Parent age:*				
At least 1 parent less than 60 years old	90	(198)	82	(216)
No parent less than 60 years old	10	(23)	18	(46)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

a/ "Urban" means living in 1 of 10 Washington counties located within a Standard Metropolitan Statistical Area, as identified in the 1980 Census: Benton, Clark, Franklin, King, Pierce, Snohomish, Spokane, Thurston, Whatcom, and Yakima Counties.

*$p < .05$

Developmental Disabilities and Health

Although the types of developmental disabilities prevalent in each study group were similar, there were differences in the degree of retardation reported for mentally retarded clients in each group (Table 2.2). Fifty-four percent of the mentally retarded persons within Group B were in the borderline to mild range, compared to 44 percent for Group A. Thus, more clients who remained at home tended to be more severely retarded than those who moved away.

TABLE 2.2

NATURE AND EXTENT OF DEVELOPMENTAL DISABILITY
AS DOCUMENTED IN DDD CASE RECORDS
BY STUDY GROUP

	Group B (N=217) %	Group A (N=264) %
Developmental disability:		
Mental retardation (MR) only	70	71
MR with another disability	17	17
MR without further information	5	6
Cerebral palsy (without MR)	6	4
Epilepsy (without MR)	1	2
Other disability (without MR)	2	1
Level of mental retardation:* (excluding clients without MR)	(N=198) %	(N=247) %
Borderline a/	28	25
Mild	26	19
Moderate	21	28
Severe	10	12
Profound	1	2
Unspecified	14	14

a/ "The previous American Association on Mental Deficiency classification system included the Borderline category, which was used for individuals who scored between one and two standard deviations below the mean on I.Q. tests. The Borderline level has been dropped from the system." Manual on Terminology and Classification in Mental Retardation. H. J. Grossman (Ed.) American Association on Mental Deficiency/Special publication No. 2, 1973. However, the Borderline category still occurs on DDD client records.

*p < .05

The health status of Group B clients was similar to Group A: Nearly 90 percent were reportedly in good health during the year prior to leaving home. Aside from their primary disabilities, Group B clients had fewer chronic health problems that required professional care (21% versus 30%).

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Reports from parents suggest that mental/emotional health problems may have been more common among Group B clients during their last year at home than among Group A clients. Forty percent of Group B were characterized as having fair to poor mental health at that time, whereas 24 percent of Group A were said to have mental health needs that were not being addressed.

Client Functioning

The parent interview included a series of items about how the client was functioning during his/her last year at home, including performance in personal care activities (self-help), communication, and social interactions. Additional items covered the presence of dangerous and non-dangerous behavior problems. Parents were asked to describe the client's actual performance, rather than to estimate his or her capabilities or motivation. For each area of client functioning a summary index was constructed from related items. This reduced the raw data to manageable form and simplified comparisons of client performance on related items.

TABLE 2.3

DESCRIPTION OF INDICES MEASURING CLIENT FUNCTIONING

Index a/	Description	Positive (+) or Negative (-) Correlation with Key Items/Indices b/	Differences between Groups A and B c/
Personal care skills (Table B.1)	Describes degree of independence in 7 self-help activities, e.g., eating, dressing.	Communication skills (+) Need for home supervision (-) Need for community supervision (-)	None
Communication skills (Table B.2)	Describes whether or not client is verbal, able to express self and understand others in his/her communication mode.	Personal care skills (+) Level of mental retardation (-)	Group A higher than Group B*
Social skills (Table B.3)	Describes appropriateness of client's behavior in public and ability to get along with others.	Dangerous behavior problems (-) Non-dangerous behavior problems (-) Need for home supervision (-) Mental/emotional health status (+)	Group A higher than Group B*
Dangerous behavior problems (Table B.4)	Describes whether or not client harms self, harms others, or destroys property.	Social skills (-) Non-dangerous behavior problems (+) Mental/emotional health status (-)	None
Non-dangerous behavior problems (Table B.5)	Describes whether or not client has temper tantrums, is deliberately disobedient, or has severe hyperactivity.	Social skills (-) Dangerous behavior problems (+) Mental/emotional health status (-)	Group B higher than Group A*

a/ Tables cited above, which appear in Appendix B, list index items and the frequency of responses by study group.

b/ This refers to variables for Group B only. A positive correlation indicates that for a pair of variables as one increases the other increases, or as one decreases the other decreases. A negative correlation means that as one of the pair of variables increases the other decreases.

c/ These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

*p < .05

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Indices of client functioning indicated that the groups were similar in personal care skills, prevalence of dangerous behavior problems (Tables B.1 and B.4 in Appendix B), and need for supervision at home and in the community. Highlights of Group B functioning in these areas included the following:

a) Over 60 percent of the Group B clients needed no help with eating, toileting, dressing, bathing, and transferring from place to place; 67 percent needed help with personal grooming.

b) Seventy-six percent had no dangerous behavior problems (causing physical harm to themselves or others or destroying property).

c) Based on parent estimates the typical client needed some supervision at home and in the community.

Although Groups A and B were similar in most functional skills, some differences were found. During their last year at home, clients in Group B were characterized as having significantly poorer communication skills and social skills than clients who remained at home (Tables B.2 and B.3). Parents reported fewer clients in Group B than Group A who were able to get along adequately with family members (83% versus 94%), authority figures (80% versus 93%), and peers (82% versus 87%). For each non-dangerous behavior problem described (hyperactivity, temper tantrums, deliberate disobedience) the incidence was higher in Group B than Group A; for both groups the most frequent problem was deliberate disobedience (Table B.5).

Social and Community Activities

Despite reported differences in social skills between study groups, friendship patterns among clients in each group were similar. Parents of Group B clients reported that 80 percent had at least one friend during their last year at home. Clients who were attending school during that time were more likely to have friends (90%) than were non-students (70%).

Parents of clients in Group B were asked about incidents during the client's last year at home which involved client safety. The frequency of such incidents, as well as the frequency of police contact about clients, did not differ significantly between study groups (Table 2.4). The most frequent problem was having money or property stolen. Less than 3 percent

TABLE 2.4

CLIENT EXPOSURE TO RISK BY STUDY GROUP*

	Group B		Group A	
	%	n	%	n
Lost or missing:				
Yes	8	(18)	9	(23)
No	92	(204)	91	(240)
Money or property stolen:				
Yes	16	(35)	15	(38)
No	84	(182)	85	(221)
Problems with drugs or alcohol:				
Yes	5	(12)	2	(5)
No	95	(212)	98	(258)
Sexually exploited:				
Yes - Rape/Incest	1	(3)	1	(2)
Yes - Indecent liberties	0.5	(1)	2	(4)
Yes - Voluntary sexual activity	0.5	(1)	0	(0)
No sexual exploitation	98	(218)	98	(256)
Physically assaulted:				
Yes - Injuries did not require professional attention	4	(8)	3	(7)
Yes - Injuries required professional attention	1	(3)	2	(5)
No physical assault	95	(212)	95	(250)
Police contact:				
Yes - As perpetrator of a crime	7	(15)	6	(17)
Yes - As victim	1	(3)	2	(4)
Yes - As neither perpetrator nor victim	6	(14)	2	(6)
No police contact	86	(191)	90	(236)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

* There were no significant differences between study groups.

had experienced incidents of sexual exploitation, which included rape, incest, indecent liberties, and voluntary sexual activity. 1/

Fourteen percent of Group B families reported that during the client's last year at home they had contact with the police about the client. Nearly one-third of these contacts involved situations where the client was reported lost or missing. Reports of crimes allegedly committed by clients (7% overall) most often involved disturbing the peace; other crimes included physical assault, theft, malicious mischief, indecent exposure, and falsely reporting a crime. In most instances the client was not arrested. Police contacts concerning clients as victims (1% overall) included incidents of physical assault, theft and robbery.

Scheduled Activities

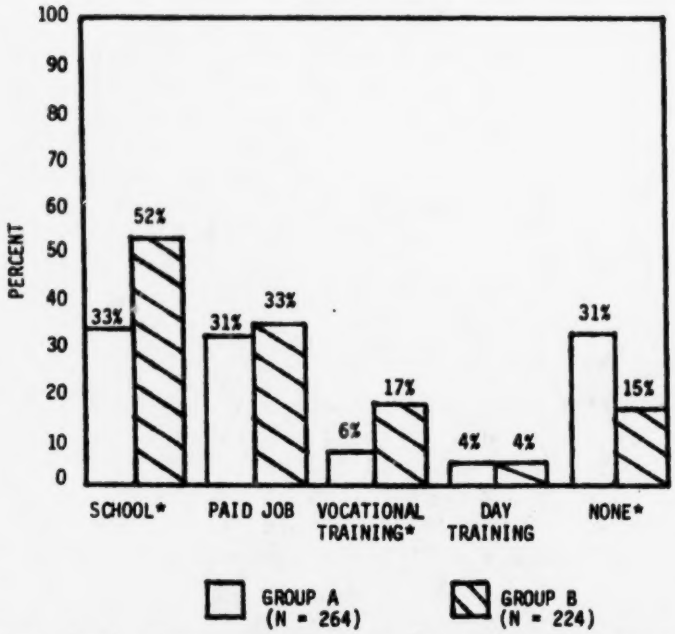
Client involvement in regularly scheduled activities--work, school, vocational training, and day training programs--differed significantly between study groups (Figure 2.1). Clients in Group B were more likely to participate in at least one of these activities: 85 percent versus 69 percent of Group A. Of the four scheduled activities, the average Group B client participated in 1.1 activities; this dropped to .7 for Group A.

As illustrated in Figure 2.1, there were more students in Group B (before they moved) than in Group A. On the average, Group B clients left school at a younger age than Group A clients (ages 19 and 20, respectively), yet in both groups the most common age for leaving school was 21. Among non-students, those in Group B were more often employed (55%) than those in Group A (45%). However, the average number of hours worked was the same for each group: 25 hours per week.

1/ Voluntary sexual activity is included because in some cases it may meet the legal definition of second degree rape (RCW 9A.44.050, Rape in the Second Degree). This law includes a clause to protect individuals deemed "incapable of informed consent" due to mental or physical handicap; a judge decides whether handicapped persons are capable of informed consent on a case by case basis.

FIGURE 2.1

PARTICIPATION IN WORK, SCHOOL, AND TRAINING BY STUDY GROUP



Note. Total of percentages reported within each study group exceeds 100% due to participation in more than one program. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

* $p < .05$

Regardless of student status, clients in Group B typically spent more total time per week in scheduled activities than Group A clients (Table 2.5). Also, there were significantly more Group B clients who spent at least 25 hours per week in scheduled activities: 70 percent versus 47 percent for Group A. 2/

2/ "Habilitation Standards to House Bill 270" (Division of Developmental Disabilities, November 1983) states that "...every eligible person will have access to at least five hours of habilitation per day, five days a week, away from where they live." Habilitative services are defined as "employment, education, vocational habilitation, therapy and related services," which are consistent with the "scheduled activities" discussed in this report.

TABLE 2.5

AVERAGE TOTAL HOURS PER WEEK SPENT IN SCHEDULED ACTIVITIES
FOR STUDENT AND NON-STUDENTS BY STUDY GROUP

	Group B		Group A	
	$\bar{X}$	n	$\bar{X}$	n
Students*	34	(107)	28	(82)
Non-students*	18	(95)	13	(166)
Total*	26	(202)	18	(248)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

*$p < .05$

Supports for the Family

As with Group A, most parents of Group B clients (82%) reported that during the client's last year at home they spent evenings out without the client, and about half (53%) said they took overnight trips alone during that time. Slightly fewer families in Group B reported having someone to care for the client if an emergency arose: 78% versus 86% of Group A.

Families were also asked how much the client's presence at home restricted them in each of the following ways: participation in activities with other family members, pursuit of special interests, and working outside the home. An index of parents' perceived restrictiveness (Table B.6) revealed no significant differences between study groups in the extent to which parents felt restricted by the client's presence at home. Parents most often reported that caring for the client restricted their opportunities to work outside the home (34% for Group B and 29% for Group A). As with Group A, there was a strong positive correlation between parents' perceived restrictiveness and clients' needs for supervision at home and in the community. 3/

The nature and extent of family involvement with DDD during the client's last year at home (for Group B) or during the past year (for Group A) did not differ between study groups. Within Group B, 70 percent of the families indicated that their relative had been a DDD client in the year before the move. Sixty-two percent reported at least one contact with Field Services during that time, and the majority of these (60%) described the quality of assistance received as "good" or "excellent".

3/ A positive correlation indicates that for a pair of variables as one increases in value the other increases, or as one decreases the other decreases. Conversely, a negative correlation means that as one of the pair of variables increases the other decreases. However, cause and effect relationships cannot be inferred.

The percentage of families who reported receiving DDD family support services and the type of services received were similar for both groups (Table B.7). According to parent reports, 77 percent had not received any DDD family support services during the client's last year at home. The support services most frequently received were respite care (16%), therapy (7%), and family counseling (4%).

Families in Group B whose relatives were DDD clients before they moved away were asked about their needs for DDD family support services during the client's last year at home. For the most part, their needs were similar to the needs reported by families in Group A (Table 2.6). However, significantly more parents in Group B indicated having had a need for family counseling.

TABLE 2.6

NEED FOR DDD FAMILY SUPPORT SERVICES
BY STUDY GROUP

	Group B		Group A	
	%	n	%	n
Respite care:				
Not received, but needed	11	(18)	13	(35)
Not received, not needed	66	(105)	65	(170)
Received, but inadequate	6	(9)	3	(9)
Received and adequate	16	(26)	18	(46)
Special equipment:				
Not received, but needed	6	(9)	4	(11)
Not received, not needed	92	(148)	95	(250)
Received, but inadequate	1	(1)	0	(0)
Received and adequate	1	(2)	1	(2)
Home remodeling:				
Not received, but needed	6	(10)	7	(18)
Not received, not needed	94	(151)	92	(243)
Received, but inadequate	0	(0)	0	(0)
Received and adequate	0	(0)	1	(2)
Therapy:				
Not received, but needed	33	(52)	37	(96)
Not received, not needed	57	(90)	58	(152)
Received, but inadequate	6	(9)	2	(4)
Received and adequate	4	(6)	3	(8)
Attendant care:				
Not received, but needed	7	(12)	7	(19)
Not received, not needed	92	(148)	89	(234)
Received, but inadequate	0	(0)	1	(2)
Received and adequate	1	(1)	3	(8)
Family counseling:*				
Not received, but needed	27	(43)	17	(43)
Not received, not needed	68	(109)	79	(205)
Received, but inadequate	3	(5)	1	(2)
Received and adequate	2	(3)	3	(9)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

*$p < .05$

CHAPTER III. MAKING THE DECISION FOR THE CLIENT TO LIVE AWAY FROM HOME

A key purpose of the parent interview was to determine the circumstances surrounding the decision for the client to live away from home. Following a discussion of when families made the decision, this chapter summarizes the major factors families considered in the decision. The final section describes the types of residential settings where clients moved initially (and in some cases, secondarily) and discusses relationships between client/family characteristics and choice of residential settings.

When the Decision was Made

Parents were asked when and at what age the client moved away from home since the age of 18. Clients moved away from home between the ages of 18 and 29, and over half (62%) were 21 years old or less. Two-thirds of the parents reported that the family discussed plans for the move at least six months before it occurred.

Approximately three-fourths of the families reported involvement with DDD during the year before the client moved from home, and 60 percent said their relative had been a DDD client for more than six months before the move. Those who moved when they were younger were less likely to have been DDD clients at that time.

Factors Considered in the Decision to Move

Ninety percent of the parents indicated that there was general agreement among family members concerning the decision. In most instances of disagreement (7%) the client wanted to move and the parent(s) disagreed. After the decision was made, over three-fourths of the families did not expect the client to return to live with them later.

Parents were asked whether any of 11 factors contributed to the decision for the client to move (Table 3.1). Most families reported that 3 to 6 factors affected the decision-making process. The reasons cited most frequently included seeking a change in social opportunities for the client (80%), the client becoming an adult (71%), and availability of housing or residential programs (60%). Factors cited least frequently included a change in the family situation (e.g., divorce, birth or death of a family member) and financial circumstances.

Reasons were also analyzed according to their primary focus--either the client, other family members, or the family as a whole. The most common reasons were client-centered: social opportunities, special services, and vocational opportunities for the client, as well as the client's transition to adulthood. However, 42 percent of the respondents indicated that the poor health of other family members was a consideration.

TABLE 3.1

FACTORS CONTRIBUTING TO THE DECISION FOR THE CLIENT TO MOVE AWAY FROM HOME
(N=224)

Contributing Factors Reported by Parents:	%	Correlation with Key Items/Indices	Value of r*
Seeking a change in social opportunities for the client	80	None	
Client's reaching adulthood	71	None	
Availability of housing or residential program	60	Length of time spent planning the move	-.23
Client's need for special services	50	None	
Client's behavior at home or outside the home	45	Client's social skills	-.41
		Client's dangerous behavior problems	.45
		Client's non-dangerous behavior problems	.52
		Client's mental/emotional health status	-.49
		Client's need for home supervision	.23
		Having police contact about the client	.22
		Extent of client friendships	-.28
		Client satisfaction with social life	-.29
		Parent's physical health status	-.31
		Extent parents felt restricted	-.36
Client's school or work opportunities	42	None	
Health/well-being of other family members	42	Client's social skills	-.25
		Client's dangerous behavior problems	.40
		Client's non-dangerous behavior problems	.29
		Client's mental/emotional health status	.32
		Client's need for home supervision	.30
		Client's need for community supervision	.30
		Parent's physical health status	-.31
		Extent parents felt restricted	.43
Client's health or physical needs	28	Client's chronic health problems	.28
		Client's mental/emotional status	-.25
		Client's need for home supervision	-.27
		Major stress experienced prior to the move	.22
		Parent's physical health status	-.24
		Independence of client's current residential setting	-.21
Concern about room for the client or special physical accommodations	26	None	
Change in the family situation (e.g., divorce, new family member)	17	Major stress prior to the move	.34
Financial circumstances	13	None	

Note. The contributing factors were scored as follows: if parents said a factor contributed to the decision for the client to move it was coded 1; if not, it was coded 0. Each factor was tested for correlation with other variables (key items and indices reported in the right-hand column). The correlation coefficient (value of r) indicates the strength and direction of the relationship between a contributing factor and the variable in the right-hand column. For example, parents who reported that the availability of housing contributed to the decision were more likely to spend less time planning the move, as indicated by r = -.23.

*p < .001

Three reasons, the health of other family members, the client's health and the client's problem behavior, correlated significantly with several variables (Table 3.1). Parents who acknowledged one or both of these factors were more likely to characterize the client during his/her last year at home as having poor social skills, having serious behavior problems, having fair to poor mental/emotional health, and needing close supervision at home or in the community. These parents were also more likely to indicate that they, themselves, were in fair to poor health and felt very restricted by their responsibilities for the client while he or she was living at home.

The reasons stated by parents for the clients moving away from home were not associated with any of the following client/family characteristics: (1) client's age, physical health status, level of mental retardation (from DDD case records), or personal care skills; (2) parent's age or marital status; and (3) family experiences such as major stress or DDD services sought but not received.

Where the Clients Moved

Table 3.2 shows the clients' initial and current residential settings after they moved from home. The majority of clients (53%) moved from the family home to a regular group home. Another 21 percent moved to independent settings, including tenant support and alternative living arrangements where intermittent staff support was provided. Eighteen percent moved to non-DDD residential settings such as nursing homes, adult family homes, and congregate care facilities. Less than 10 percent moved to specialized group homes, community institutions for the mentally retarded, or Residential Habilitation Centers (state institutions for the mentally retarded).

Residential settings were ranked according to their relative level of independence. From most to least independent, these settings were as follows: (1) independent living, relative's home, tenant support or alternative living; (2) adult family home, congregate care facility, boarding home; (3) regular group home; (4) specialized group home, nursing home, community institution for the mentally retarded; and (5) Residential Habilitation Centers. 4/

4/ The rank order of settings was adapted from Cox, W. M.; Drake, H. M.; and Johnson, G. (1983). A Descriptive Study of Persons with Developmental Disabilities Living in Regular Group Homes, Tenant Support and Alternative Living. Washington State Department of Social and Health Services, Olympia, Washington.

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TABLE 3.2

FIRST RESIDENTIAL SETTING AFTER LEAVING HOME AND CURRENT RESIDENTIAL SETTING

1st Residential Setting After Leaving Home	Current Residential Setting													
	IND	REL	TS	AFH	CCF	BH	RGH	SGH	NH	IMR	RHC	NI	TOT	%
Independent Living (IND)	22		1				1						24	11%
Other Relative (REL)	1												1	0%
Tenant Support (TS)	5		13	1			1		1				21	10%
Adult Family Home (AFH)	1		1	8	1	1	1			1			14	6%
Congregate Care Facility (CCF)			2		5		1						8	4%
Boarding Home (BH)	1		1										2	1%
Regular Group Home (RGH)	18	1	14	2	1		75		3		1		115	53%
Specialized Group Home (SGH)			1				1	2					4	2%
Nursing Home (NH)			2				1		11		2	1	17	7%
Community IMR-C,D (IMR)										1			1	0%
Residential Habilitation Center (RHC)	1		1				4				7		13	6%
No Information (NI)												4	4	2%
Total Number (TOT)	49	1	36	11	7	1	85	2	15	2	10	5	224	100%
Percentage of Total (%)	22%	0%	16%	5%	3%	0%	39%	1%	7%	1%	5%	2%	100%	

Note. Numbers within the diagonal lines represent clients who remained in their initial residential setting. Numbers to the left of the diagonal represent clients who moved again to less supervised settings after their initial move. Numbers to the right of the diagonal represent clients who moved to more supervised settings since their first move away from home.

Analyses were performed to determine if there were any relationships between degree of independence of residential setting (after the client left home) and other variables, such as when the client moved, factors related to the decision to move, and client/family characteristics prior to the move. No correlations were found between degree of independence of residential setting and the year the client moved or the client's age when the move occurred. Only one decision factor correlated with residential setting: Clients whose families reported that "health or well-being of other family members" contributed to the decision tended to move to less independent residential settings (r=.24).

Information about where the clients currently resided showed that two-thirds of the clients had not changed residential settings since their initial move from home (numbers within diagonal line in Table 3.2). Twenty-six percent moved into more independent settings, most frequently from regular group homes to independent living (numbers left of diagonal in Table 3.2). Eight percent moved to less independent residential settings (numbers right of diagonal in Table 3.2).

Several client/family characteristics were associated with the degree of independence of the clients' residential settings after moving away from home (Table 3.3). Moving to a more independent setting was associated with clients who had higher personal care skills, required less supervision at home and in the community, and parents who felt less restricted by the responsibilities of caring for the client at home. Conversely, clients who needed more supervision at home and in the community, had lower personal care skills, and whose parents felt more restricted tended to move to less independent residential settings.

TABLE 3.3

CORRELATIONS BETWEEN SELECTED CHARACTERISTICS AND DEGREE OF INDEPENDENCE IN RESIDENTIAL SETTINGS (N=224)

	Degree of Residential Independence	
Characteristics a/	First Residence	Current Residence
Personal care skills	.35*	.40*
Need for home supervision	-.38*	-.40*
Need for community supervision	-.28*	-.34*
Parent perceived restrictiveness	-.26*	-.29*
Degree of mental retardation	-.19	-.29*
Communication skills	.18	.25*

a/ These data pertain to the year before the client moved away from home.

*p < .001

Pearson correlation coefficients were also computed to determine if the same characteristics associated with the level of independence of the client's first residential setting were also associated with the client's current residential setting (Table 3.3). The correlation coefficients of the four characteristics associated with degree of independence at the first residential setting all increased with the current residential setting. Two additional client characteristics were associated with degree of independence at the current residential setting: degree of mental retardation and communication skills. Thus, clients' functional skills were more strongly associated with degree of residential independence for their current living situation than for the initial living situation. This suggests that their current living situations are more consistent with their functional skills.

CHAPTER IV. CLIENT STATUS--CURRENT AND FUTURE

To determine the current status of DDD clients who had moved away from home, families were asked a series of questions about the client's present circumstances. Because Group B clients were no longer living with their families, it was necessary to confirm that the respondents were knowledgeable about the current status of their developmentally disabled relatives. Parents were asked how recent and frequent their contacts with the client had been. Most parents (90%) had visited the client at least once during the previous month, and all had been in contact with the client within the last six months. Parents were also asked about plans and provisions that had been made for the client's future.

Current Status of Clients

Parents were asked to indicate their satisfaction with the client's current residential setting, weekly routine, social life, and mental or physical health, using a scale from very satisfactory to very unsatisfactory. Results indicated that for each item at least 80 percent of the families considered the current situation satisfactory (Table 4.1). Generally, the degree of satisfaction or dissatisfaction reported was consistent across items (Table B.9). Response patterns across all four items showed that 76 percent of the respondents were satisfied with all of the client's current circumstances. Three percent described every aspect as unsatisfactory.

TABLE 4.1

PARENTS' SATISFACTION WITH THE CLIENTS' CURRENT STATUS

	%	n
Current living arrangement:		
Very satisfactory	43	(93)
Satisfactory	45	(98)
Unsatisfactory	11	(24)
Very unsatisfactory	1	(3)
Current weekly routine (e.g., job, school, training program):		
Very satisfactory	35	(74)
Satisfactory	46	(96)
Unsatisfactory	17	(35)
Very unsatisfactory	2	(4)
Current social life:		
Very satisfactory	28	(58)
Satisfactory	52	(109)
Unsatisfactory	18	(38)
Very unsatisfactory	2	(4)
Current mental or physical health:		
Very satisfactory	29	(61)
Satisfactory	56	(117)
Unsatisfactory	14	(30)
Very unsatisfactory	3	(6)

Arrangements for the Client's Future

Parents were asked about plans they had made for the client's future. Sixty percent had made financial arrangements, the most common of which were inheritance and trust fund provisions for the client. Forty percent had made no financial arrangements and 54 percent said they needed information on financial planning. Among families in which both parents--or single parents--were age 60 or older (10% overall), over three-fourths had made some sort of financial provisions for the client. On the other hand, half of the families with both parents--or single parents--in fair to poor health (11% overall) had made no financial arrangements for the client.

When asked who would assume responsibility for the client after the death of the parent(s), 40 percent indicated that no arrangements had been made, 40 percent had appointed a legal guardian and 20 percent had designated a sponsor/advocate. Families in which the parent(s) were 60 years old or more, or in fair to poor health, were no more likely to have made sponsorship arrangements for their children than families in which the parent(s) were younger or in better health.

Whether or not families had made arrangements for the client's future was examined on the basis of the following client characteristics: age, level of mental retardation documented in DDD case records, and functional performance prior to the move (communication and personal care skills, need for home and community supervision). None of these variables appeared to be associated with the likelihood that financial arrangements had been made for clients studied. However, some differences were found in characteristics between clients with and without sponsorship arrangements: clients with greater needs for home and community supervision and fewer personal care skills were more likely to have a designated guardian or sponsor.

APPENDIX A

METHODOLOGY FOR GROUP B

Study Group Selection

Clients selected for Group B had to meet four criteria: (1) enrollment as a DDD client, (2) between the ages of 22 and 29 years old, (3) not currently living with a relative or guardian, and (4) living at home at the age of 18. In order to identify clients who met these criteria, a detailed screening procedure was necessary (Table A.1). First, a list of all clients in this age group who were not living with their families was generated, using the population data file of all DDD Field Services clients statewide as of November 15, 1983. There were 1,261 clients so identified. Attempts were then made to contact the relative/guardian of each client by telephone or mail to determine if the client was living at home at age 18, as this was a criterion for inclusion in this study group. About half of this group were never fully screened: either they could not be located, were eliminated because of their participation in the previous DDD research study,5/ or refused to answer screening questions. Of the 658 families who were contacted and screened, 272 Field Services clients were identified as appropriate for Group B.

TABLE A.1

SCREENING AND STUDY GROUP SELECTION

Description	No. of Cases
DDD Field Services clients, ages 22-29, not living at home	1261
Incomplete and duplicate records	-177
Former study participants	-50
Total candidates for screening	1034
Refused screening	-14
Could not be located	-362
Clients screened based on Group B criteria	658
Rejected as inappropriate for Group B	-386
DDD Field Services clients considered appropriate	272
RHC residents considered appropriate	+16
Total parent interviews attempted	288
Refused interview	-28
Could not be reached	-28
Interviews terminated or cancelled	-8
Total parent interviews completed	224

5/ Cox, W. M.; Drake, H. M.; and Johnson, G. (1983). A Descriptive Study of Persons with Developmental Disabilities Living in Regular Group Homes, Tenant Support, and Alternative Living. Washington State Department of Social and Health Services, Olympia, Washington.

Through information provided by the DDD Residential Habilitation Centers (RHCs), 16 residents of state institutions for mentally retarded persons were identified as appropriate and added to the study group. Therefore, a total of 288 clients were selected for Group B. Attempts were made to contact the nearest relative or guardian of these clients and request their participation in a telephone interview.

When the study group was identified, the DDD population file was used to verify that it represented the population from which it was drawn: 1261 Field Services clients, ages 22-29, not living at home. Comparisons of these distributions for sex, urban or non-urban status, developmental disability and level of mental retardation confirmed that the study group was representative of the total population of DDD clients aged 22 to 29, who were not currently living with a relative or guardian (Table A.2).

TABLE A.2

COMPARISON OF POPULATION AND
STUDY GROUP CHARACTERISTICS FOR GROUP B

	Population a/		Study Group b/	
	%	n	%	n
Sex:				
Male	53	(659)	51	(113)
Female	47	(591)	49	(109)
Locale:				
Urban	75	(946)	73	(162)
Non-urban	25	(315)	27	(60)
Developmental Disability:				
Mental retardation (MR) with or without another disability	94	(1,185)	91	(198)
Cerebral palsy (without MR)	4	(45)	6	(12)
Epilepsy (without MR)	1	(7)	1	(2)
Other disability (without MR)	2	(24)	1	(5)
Level of mental retardation: (Only MR clients)				
Borderline	24	(284)	28	(55)
Mild	23	(270)	26	(52)
Moderate	23	(274)	21	(41)
Severe	13	(157)	10	(20)
Profound	6	(68)	1	(2)
Unspecified	11	(130)	14	(28)

a/ The population consisted of the 1,261 DDD Field Services clients, ages 22-29, identified as not living at home, (not screened for whether they lived at home at age 18).

b/ The study group consisted of the 224 clients who were screened as appropriate for Group B and for whom there were completed parent interviews.

Data Collection

Information about Group B clients was collected from two sources. Each client's name, address, age, sex, DD Specialist, parent or guardian, and living situation was obtained from the DDD population file (for Field Service clients) or from institution records (for RHC residents). Information on the clients' functional abilities and needed supports, daily routines, living environments, and sources of support during their last year at home, as well as their future needs and goals, was obtained through telephone interviews with relatives or guardians.

The parent interview questionnaire was developed by research staff in concert with staff from DDD. It consisted of about 200 items, which generally took 40 to 45 minutes to administer. About two-thirds of the items were similar to questions asked in interviews about clients from Group A, which facilitated comparisons between the two groups. The remainder of items focused upon circumstances surrounding the client/family decision for the client to move from the family home.

The majority of interview items pertained to the year before the client moved away from home, which ranged from 1 month to 11 years prior to the interview. It is important to note that, whereas data about Group A refer to the year prior to the interview, most Group B data refer to an earlier time period (an average of five years before the interview).

The interview team consisted of the same five interviewers who conducted the Group A telephone interviews. As a result, by the time Group B data collection began the interviewers had already received extensive training and experience interviewing parents of developmentally disabled adults. The closest relative or guardian of each client in the sample was contacted and requested to participate in a voluntary telephone interview. Out of 288 possible interviews the rate of completed interviews was 78 percent (N=224).

Reliability

Many of the results from Group A reliability tests were utilized to enhance Group B efforts.6/ Consequently, fewer reliability measures were necessary during data collection for Group B. Again, practice interviews were conducted with surrogate respondents to achieve high consistency among interviewers in how items were asked, recorded, and coded. Performance of the interview team was routinely monitored to ensure that high inter-rater reliability was maintained. Also, at the close of each interview the interviewer rated the respondent's attentiveness, comprehension, and overall reliability. Data from respondents with two or more "poor" ratings were to be excluded from analysis, but the situation did not arise.

6/ Cox, W. M. and Wilson, W. (1985). Developmentally Disabled Persons in Family Settings: Report No. 1. Washington State Department of Social and Health Services, Olympia, Washington.

Data Analysis

The data were keyed onto tape at DSHS headquarters in Olympia. The raw data were then run through range and logic edit programs and corrected before a system file was created using SPSS-X (Statistical Package for the Social Sciences, Version X). The DDD Field Services data and the parent survey data for Group B were merged with Group A data into one master file to facilitate comparative analyses between the groups.

Some data reduction was performed by constructing summary indices for related item subsets. Two types of indices were created. The first type, which will be referred to as "count indices," were made up of dichotomized variables (e.g., yes = 1, no/don't know = 0). These indices were constructed by counting the number of "yes" responses (value = 1) across all items in the index for each case. The maximum index score is equal to the number of items in the index; the lowest index score is zero. The count indices included communication skills, dangerous behavior problems, non-dangerous behavior problems, and family support services provided by DDD.

The second type of index was made up of items with more than two response values (e.g., never = 1, sometimes = 2, often = 3). In this case the response values were summed across all items in the index for each case, with item means substituted for items with missing values. For this type of index the maximum index score is equal to the sum of the highest values of all items in the index. The summed indices were personal care skills, social skills, and parent perceived restrictiveness.

A reliability analysis of index components was performed by computing Cronbach's alpha test for internal homogeneity. This is a standard test of internal consistency among items used to construct an index. 7/ When alpha is squared it becomes the coefficient of reliability, which equals the portion of variance shared by all items used to construct the index. It was decided that if items shared at least 49 percent of the total variance that the internal consistency of the index was sufficient for the purposes of this study. Thus, indices with an alpha of .70 or greater were used in analysis. All items used to construct each of the indices discussed in the text are presented in Appendix B.

Only Group A clients aged 18 through 26 were used in comparisons with Group B clients. These clients had the same average age (21) and age range as Group B clients during their last year living at home.

The primary mode of data analysis was descriptive. Frequency distributions, means, and medians were generated across all data items. Tests of statistical significance within and between groups were performed on selected data. Data reported in percentage format were evaluated with the Chi-square statistic; data reported as averages were subject to a one-way analysis of variance and were evaluated with the F statistic. Relationships among items and indices were analyzed by computing Pearson correlation coefficients to determine the direction and strength of associations.

7/ Cronback, L. "Coefficient Alpha and the Internal Structure of Tests." Psycometrika, XVI. 1951, pp. 297-344.

APPENDIX B

TABLES

Tables B.1 through B.7 describe summary indices, listing the items included in each index, the frequency of responses, and other relevant statistics. Tables B.8 and B.9 each present correlations of selected study variables.

TABLE B.1

PERSONAL CARE SKILLS INDEX

AMOUNT OF HELP NEEDED WITH PERSONAL CARE ACTIVITIES	B (N=224) %	A (N=264) %
Eating:		
4 - None	85	82
3 - Some	10	11
2 - A lot	2	4
1 - Total	2	3
Dressing:		
4 - None	74	74
3 - Some	13	15
2 - A lot	8	5
1 - Total	5	6
Using toilet:		
4 - None	81	77
3 - Some	10	13
2 - A lot	4	4
1 - Total	5	6
Bathing:		
4 - None	63	56
3 - Some	23	25
2 - A lot	4	10
1 - Total	9	9
Grooming:		
4 - None	33	30
3 - Some	47	47
2 - A lot	14	12
1 - Total	7	11
Moving about:		
4 - None	86	89
3 - Some	8	6
2 - A lot	3	0
1 - Total	3	5
Transferring:		
4 - None	91	92
3 - Some	4	2
2 - A lot	1	1
1 - Total	4	5

No. of items: 7
Range of values: 7 = minimum
28 = maximum

$\bar{X}$ Scores: 25.0 (B)
24.7 (A)
Standard deviation: 4.3 (B)
4.8 (A)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

TABLE B.2

COMMUNICATION SKILLS INDEX*

COMMUNICATION SKILLS	B (N=224) %	A (N=264) %
How client communicates with others:		
1 - Verbal	88	85
0 - Non-verbal	12	15
0 - Don't know	0	0
Ability to understand:		
1 - Understands simple sentences	90	98
0 - Does not understand simple sentences	9	0
0 - Don't know	1	2
Ability to express self outside family:		
1 - Uses simple sentences	76	100
0 - Does not use simple sentences	24	0
0 - Don't know	0	0

No. of items: 3
Range of values: 0 = minimum
3 = maximum

$\bar{X}$ Scores: 2.5 (B)
2.8 (A)
Standard deviation: .3 (B)
.4 (A)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

* $p < .05$

TABLE B.3

SOCIAL SKILLS INDEX*

SOCIAL BEHAVIOR	B (N=224) %	A (N=264) %
Gets along with family:		
3 - Very well	53	64
2 - Adequately	30	30
1 - Not very well	16	6
0 - Don't know	0	0
Gets along with authorities:		
3 - Very well	47	62
2 - Adequately	33	31
1 - Not very well	17	5
0 - Don't know	2	2
Gets along with peers:		
3 - Very well	46	54
2 - Adequately	36	33
1 - Not very well	16	9
0 - Don't know	3	4
Behavior with persons outside the family:		
3 - Usually appropriate	72	74
2 - Sometimes appropriate	24	22
1 - Seldom appropriate	4	3
0 - Don't know	0	1

No. of items: 4
Range of values: 4 = Minimum
12 = Maximum

$\bar{X}$ Scores: 9.5 (B)
10.2 (A)
Standard deviation: 2.3 (B)
1.8 (A)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

* $p < .05$

TABLE B.4

DANGEROUS BEHAVIOR PROBLEM INDEX

CLIENT HAS A SIGNIFICANT BEHAVIOR PROBLEM	B (N=224) %	A (N=264) %
Causing physical harm to others:		
1 - Yes	13	12
0 - No	86	88
0 - Don't know	1	0
Causing physical harm to self:		
1 - Yes	12	11
0 - No	87	89
0 - Don't know	0	<1
Destroying property:		
1 - Yes	13	11
0 - No	85	89
0 - Don't know	1	0
NONE OF THE ABOVE:	76	78

No. of items: 3
Range of values: 0 = Minimum
3 = Maximum

$\bar{X}$ Scores: .4 (B)
.3 (A)
Standard deviation: .8 (B)
.7 (A)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

TABLE B.5

NON-DANGEROUS BEHAVIOR PROBLEM INDEX*

CLIENT HAS A SIGNIFICANT BEHAVIOR PROBLEM	B (N=224) %	A (N=264) %
Severe hyperactivity:		
1 - Yes	17	9
0 - No	81	89
0 - Don't know	2	2
Temper tantrums:		
1 - Yes	33	28
0 - No	66	72
0 - Don't know	1	0
Disobey rules:		
1 - Yes	36	30
0 - No	63	69
0 - Don't know	1	1
NONE OF THE ABOVE:	48	54

No. of items: 3
Range of values: 0 = Minimum
3 = Maximum

$\bar{X}$ Scores: .9 (B)
.7 (A)
Standard deviation: 1.0 (B)
.8 (A)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

* $p < .05$

TABLE B.6

PARENT PERCEIVED RESTRICTIVENESS INDEX

HOW MUCH PARENTS FEEL THAT HAVING A HANDICAPPED CHILD	B (N=224) %	A (N=264) %
Restricts family activities:		
1 - None	51	47
2 - Some	31	31
3 - A lot	17	21
0 - Don't know	1	1
Restricts opportunity to pursue interests:		
1 - None	42	40
2 - Some	37	36
3 - A lot	20	24
0 - Don't know	1	0
Restricts opportunity to work outside home:		
1 - None	47	48
2 - Some	17	21
3 - A lot	34	29
0 - Don't know	2	2

No. of items: 3
Range of values: 3 = Minimum
9 = Maximum

$\bar{X}$ Scores: 5.2 (B)
5.3 (A)
Standard deviation: 2.1 (B)
2.1 (A)

Note. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

TABLE B.7

FAMILY SUPPORT SERVICES INDEX
(PROVIDED BY DDD)

DURING PAST YEAR CLIENT RECEIVED	B (N=224) %	A (N=264) %
Respite care:		
1 - Yes	16	21
0 - No	56	79
0 - Not applicable	28	0
Special equipment:		
1 - Yes	1	1
0 - No	70	99
0 - Not applicable	28	0
Money for remodeling:		
1 - Yes	0	1
0 - No	72	99
0 - Not applicable	28	0
Therapy:		
1 - Yes	7	6
0 - No	63	94
0 - Not applicable	28	0
Attendant care:		
1 - Yes	0	4
0 - No	72	96
0 - Not applicable	28	0
Counseling:		
1 - Yes	4	4
0 - No	68	95
0 - Not applicable	28	0
NONE OF THE ABOVE:	77	70

No. of items: 6
Range of values: 0 = Minimum
6 = Maximum

$\bar{X}$ Scores: .3 (B)
.4 (A)
Standard deviation: .6 (B)
.6 (A)

Note. These items were only asked of families whose offspring were DDD clients at that time. These data pertain to the year before the client moved away from home (for Group B) and the year just prior to the parent interview (for Group A).

TABLE B.8

INTER-CORRELATIONS AMONG CLIENT/FAMILY CHARACTERISTICS
DURING THE CLIENT'S LAST YEAR AT HOME

	PCS	NHS	NCS	DBP	NBP	SOC	COM	PHS	MHS	ACT	PPH
PERSONAL CARE SKILLS (PCS)											
NEED FOR HOME SUPERVISION (NHS)	-.50*										
NEED FOR COMMUNITY SUPERVISION (NCS)	-.46*	.63*									
DANGEROUS BEHAVIOR PROBLEMS (DBP)	.07	.23*	.20								
NON-DANGEROUS BEHAVIOR PROBLEMS (NBP)	.16	.18	.04	.60*							
SOCIAL SKILLS (SOC)	-.09	-.25*	-.12	-.36*	-.52*						
COMMUNICATION SKILLS (COM)	.35*	-.25*	-.30*	.39*	.60*	-.02					
PHYSICAL HEALTH STATUS (PHS)	.13	-.18	-.06	-.12	-.07	.21	.05				
MENTAL/EMOTIONAL HEALTH STATUS (MHS)	-.12	-.20	-.14	-.43*	-.48*	.58*	-.02	-.39*			
TOTAL HRS. OF SCHEDULED ACTIVITY (ACT)	-.11	.00	.01	-.06	-.06	.36*	-.09	.10	-.01		
PARENT PHYSICAL HEALTH STATUS (PPH)	.02	-.20	-.07	-.22*	-.22*	.14	.17	-.19	-.28*	.00	
PARENT PERCEIVED RESTRICTIVENESS (PPR)	-.29*	.58*	.47*	.27*	.25*	-.27*	-.22*	-.15*	-.26*	-.01	-.21

Note. A positive coefficient (no sign) indicates that for a pair of variables as one increases in value the other increases, or as one decreases the other decreases. A negative coefficient (-) means that as one of the pair of variables increases the other decreases. Also, the square of a coefficient equals the proportion of variance shared by the pair of variables.

*$p < .001$

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TABLE B.9

INTER-CORRELATIONS AMONG REPORTS OF PARENT SATISFACTION WITH THE CLIENT'S CURRENT CIRCUMSTANCES (N=224)

Parent Satisfaction with the Client's Current Circumstances:	Living Arrangement	Weekly Routine	Social Life
Current living arrangement			
Current weekly routine	.46*		
Current social life	.48*	.40*	
Mental or physical health	.52*	.45*	.52*

Note. A positive coefficient (no sign) indicates that for a pair of variables as one increases in value the other increases, or as one decreases the other decreases. A negative coefficient (-) means that as one of the pair of variables increases the other decreases. Also, the square of a coefficient equals the proportion of variance shared by the pair of variables.

*$p < .001$

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